

Tips and reflections for organisers and others working towards a more inclusive cultural life

Here we have gathered some concrete tips for anyone who wants to organise activities for families with children with disabilities. We have also gathered reflections on what can have an impact in the longer term when working towards a more inclusive arts and cultural life.

Our collective experience from carrying out the project supports the hypothesis that *relationships matter* when it comes to overcoming barriers. We believe that building trusting relationships with families is a crucial factor in creating change towards a more inclusive arts and cultural life. The importance of relationships also applies within the sector. By building alliances with other organisations and practitioners who share the same commitment and similar aims, we can become stronger together, demonstrate examples, make the case for change and advocate for broader structural changes that can reach the highest political levels and contribute to shifts in the allocation of financial resources.

Concrete lessons in relation to families

Here we have listed the conditions that we have found can make a difference in whether families want to, are able to and feel confident enough to participate, and whether they feel expected and welcomed. These also provide very concrete tips that other organisations can make use of.

- **How families are met and treated** – both the children and the adults. Establishing good and trusting relationships with the adults is crucial, as they are the ones who make decisions about the child's and the family's free time.
- There is a need for a **broad range of activities**. Families want to have choices, just like other families in society.
- Activities need to be able to meet the **very different needs of children**. Children with multiple disabilities are one group of children who may need extensive adaptations. Another group is some autistic children, for whom the challenges may be equally significant, but where the need for adaptations may look very different.
- Activities need to be offered with **continuity over time** – not only as one-off events or short-term projects that then come to an end. There is a need to be able to try something more than once.
- There is a need for activities in public spaces for everyone *and activities specifically for families with children with disabilities*. In addition, activities are needed in other settings that can be fully tailored to the needs of the child and family. For some families, this may be a prerequisite for being able to participate.
- There is a desire and a need for activities where **families can meet each other**, and where the whole family or parts of the family can participate.
- Activities where **adaptation and flexibility** are built into the format are essential for families to feel safe. The activity should never lead families to feel that they have done something wrong or are somehow disruptive or difficult.

- A sense of **freedom from demands and expectations** within and around the activity needs to be communicated. It is important to clearly signal that it is completely OK to be exactly as you are when you arrive, and that it is also completely OK for a family to cancel at the last minute because of the child's current state or changed circumstances within the family.
- **Preparatory materials** can be helpful for some children. These may include **photos** of the **people** the child will meet during the activity, photos and/or films of the **place** where the activity will take place, and photos and/or films of the **activity** itself.
- Having a **contact person** whom families can get in touch with is important. Email may work well for some families, while text messages or speaking directly on the phone may be preferable for others.
- **Information materials** intended to reach families need to clearly signal that the activity is specifically aimed at children with disabilities. **Representation** of children with different disabilities can be helpful, as parents often look for children who "resemble" their own child in order to assess whether an activity might be worth trying.
- **Visual supports** can be another way of clearly communicating in information and promotional materials that an activity is aimed at families with children with disabilities, as many families are familiar with the use of visual supports. Visual supports can also be helpful as preparation or at the place where the activity takes place.
- If **refreshments** are offered, it is useful to **ask families** what conditions need to be in place and whether there are any allergies. This is not only about finding out *what* should be available, but also *how* the refreshments should be offered.
- The **name of the activity** can matter, as every word carries associations. Some words may suggest that a person is expected to behave in a particular way or needs to perform. This can create stress.
- If the activity is to take place over a longer period, it can be helpful to **ask families** which **weeks, days and times** work best for them.
- **Collaboration** is needed to reach families. Habilitation services can be one platform, as can adapted schools, organisations for children and young people with disabilities, or other networks and communities.
- There is a great need for **targeted efforts** to reach families who primarily communicate in **languages other than Swedish** and/or who may lack experience of and familiarity with taking part in arts and cultural activities or actively seeking out what is available. **Information materials in languages other than Swedish are essential.** It is helpful if there is a contact person who speaks the family's language.
- It matters that **the activity is free of charge**. Many families with children with disabilities have limited financial resources, for example because of part-time work needed to make everyday life manageable.

Reflections on experiences of advocacy within the sector

Here we have listed points that we see as important factors for successful long-term advocacy, as well as questions that we consider highly relevant if an equitable arts and cultural life and participation in public spaces are to become a reality for everyone.

- The hypothesis that **relationships matter** also applies to advocacy towards and within the sector. Those who make strategic decisions or determine financial priorities need to understand who the children are and how widely their needs can vary. Often, an experience or direct involvement is needed in order to build a relationship with, and a broader understanding of, the target group. These are children who very rarely or never take part in arts and cultural experiences in public spaces.
- It is important to build **networks** and **alliances** with others who want to work towards the same goals.

This can help prevent people from feeling alone, both on a personal and organisational level, when it comes to finding genuine ways to include *all* children and their wider contexts within society's arts and cultural life.

- Mapping a problem can be a starting point, but it is not enough to change exclusion and unjust and unequal conditions. **Pilot projects** are therefore important. By testing things in practice and setting something in motion, new relationships can be created and gradually become stronger. However, there is a risk that the experiences and relationships are not carried forward when projects end. There needs to be **long-term commitment to successful initiatives**.
- There is a need both for **long-term shifts in priorities** *and* highly **targeted initiatives** that can catalyse change or test a strategy.
- **The allocation of financial resources** needs to be informed by a **mindset** that considers what a child is offered throughout their upbringing and the significance this can have from a **lifelong perspective**.
- **Accessible toilets with hoists** and sufficient space for changing need to be available in public places. It is deeply problematic that these are currently so rare in public spaces.
- **Short-term cuts** and **reorganisations** can have major consequences at individual, group and sector level, and can quickly undermine progress that has taken time to achieve. Positive developments cannot be taken for granted. These issues need to be continuously monitored and addressed so that barriers can gradually be removed and more people can feel genuinely included as a matter of course.